

## **SUMMARY OF DISCUSSION**

### **NCBDDD External Partners Group Conference Call**

**Date:** Friday, May 7, 2004; **Time:** 1:30-2:30pm (EST)

**Participants:** Clarke Ross, Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD); Barbara Kilbourne, National Center on Birth Defects and Developmental Disabilities (NCBDDD); Jeremy Scott, Tourette's Syndrome Association (TSA); Serena Lowe, B&D Sagamore; Maura Archambault, B&D Sagamore; George Jesien, Association of University Centers on Disabilities (AUCD), Trista Sims (AUCD); Laurie Fletcher (AUCD). Approximately 25 other people participated in the call as observers and were given the opportunity to make comments a number of times during the call.

**Invited, but not able to attend:** Jane Correia, National Birth Defects Prevention Network (NBDPN); James Rimmer, National Center on Physical Activity & Disability (NCPAD); Lowell Sever, Past Chair of EPG.

#### ***Introductions and Overview of Agenda***

The conference call began at 1:30pm. Members of the Executive Committee followed by members of the larger Partners Group briefly introduced themselves and their organizations.

#### ***Update on Hill Lunch Briefing - April 8, 2004***

Maura A. reported on the Hill lunch briefing that was held on Thursday, April 8th from 12-1:30pm at the House Resources Subcommittee Hearing Room, 1334 Longworth House Office Building in Washington D.C. Despite the April recess, the briefing was very well attended, with approximately 32 Congressional staff (largely bi-partisan), 3 media organizations and 35 External Partners present. A total of \$2400 was donated by 24 different member organizations of the NCBDDD-EPG to help support the cost of the briefing.

The briefing was held in order to provide Congressional staff with information related to the Center's overall goals, updates on recent activities, in addition to highlighting specific issues of interest to Congress, such as newborn and child developmental screening and prevention of secondary disabilities. The briefing also highlighted the future of the NCBDDD and the Center's Strategic Initiative. Introductory remarks were made by George Jesien on behalf of the EPG and Barbara Holloway, Deputy Director of the NCBDDD, provided an overview of the Centers activities and described the Futures Initiative in which it was participating. Two other speakers addressed the attendees at the briefing. Dr. Don Bailey of the University of North Carolina at Chapel Hill, a nationally recognized researcher on Fragile X syndrome, spoke on the importance of newborn and early childhood screening. Dr. Tom Seekins of the University of Montana presented on the topic of "Promoting Quality Health through the Prevention and Management of Secondary Conditions Experienced by People with Disabilities." Finally, three persons with direct life experience of living with a disability or family members spoke. Ann Cody and Kim and Bruce Fleming, gave personal anecdotes on the critical importance of a strong public health infrastructure to support people living with

disabilities. The Agenda and pictures of the briefing are available on the NCBDDD website at <http://www.cdc.gov/ncbddd/partners/>.

**\*\*Lastly, the Executive Committee would like to thank the Partners Group for your overwhelming support and for such a strong showing at the briefing.**

### ***Congressional Visit to NCBDDD***

Serena L. reported on the possibility of inviting Hill staffers to the NCBDDD. Due to a large turnover rate on the Hill, the purpose of the Hill visit would be to educate a small group of key Congressional staff (i.e. appropriators) on the diverse group of activities of the Center. This visit would also be very helpful for the Center staff in order to promote their activities and to educate and understand how policy affects funding. It was suggested that we target upcoming recess periods such as Memorial Day weekend or the week before or after July 4<sup>th</sup>.

Barbara H. discussed the Center's capacity for visitors in that it would have to be associated with a conference in order for the Center to fund and that she would look into this possibility. An issue for Hill staff is that they do not have funds to travel, so the Partners Group may have to raise funds. Jeremy S. suggested that due to the high turnover rate of Hill staffers (not guaranteed that the Hill staffers we send to the Center will be on the Hill much longer), that we should devote resources for the Partners Group to meet with the Hill staffers at the NCBDDD conference in July since it will be in Washington, D.C. Barbara H. suggested that we can conduct the visit during the Asthma meeting during the Memorial weekend, but it was decided that the Memorial Day recess was too soon to hold such an event. The final decision was to postpone further consideration of a separate Hill meeting and to focus on Hill visits at the NCBDDD conference and Asthma conference.

### ***Update on the CDC Futures Initiative***

Barbara K. reported that the CDC Director, Dr. Julie Gerberding, is announcing a reorganization plan on Thursday, May 13<sup>th</sup> about the CDC Futures Initiative. Barbara K. will send out a notice of the announcement and is encouraging everyone to tune in. The proposed reorganization model of the CDC will be composed of a clustering of similar Centers to ensure better coordination of programs and to decrease duplication. Barbara K. also discussed her talk with Dr. Jose Cordero on how it will impact the NCBDDD. Dr. Cordero does not foresee the Center losing its visibility, however there are still possible concerns since the Center may be clustered in such a way with much larger centers that it loses its visibility and attention to its issues. Each cluster will be headed by a director to which individual center directors will report. This in effect introduces another layer between center directors and the CDC director's office.

In response to these concerns, the Executive Committee decided on a two-stage process in which we will send a short, generic letter prior to the May 13<sup>th</sup> announcement and then will send a more substantive letter after the announcement is made. The first letter will be sent out from the Executive Committee and will stress the importance of the Partners Group to the success and growth of the NCBDDD and its programs. Also, it will comment on the legislative charter and reporting requirements of the NCBDDD. It will encourage consultation with the Partners Group regarding proposed reorganization plans, as well all

other public announcements so that the NCBDDD can continue the positive partnership to more effectively promote the mission of the CDC and its various programs. The second letter will discuss in more detail any concerns that become evident after the plan is announced. Clarke R., Maura A. and Serena L. will work on drafting the two letters. The letters will be sent out to the Partners Group thereafter. For more information on the CDC Futures Initiative, visit their website at <http://www.cdc.gov/futures/>. For more information on the press release announcement, visit <http://www.cdc.gov/od/oc/media/pressrel/r040513.htm>.

### ***Update on NCBDDD 2004 Conference – July 26-28, 2004***

#### EPG Meeting Agenda

The EPG meeting will be held on Sunday, July 25<sup>th</sup> from 3-5pm. The meeting will primarily focus on the organizational development of the Partners Group. There were a few ideas on what topics should be covered during the meeting. Some suggested topics included: discussing the overall structure of the Partners Group, ways to generate funds, future activities, strategies for moving towards the future, and ways to assist in providing input to the development of a strategic research agenda. It was suggested that the Coalition for Children's Health could do a presentation on their activities.

#### Hill Event

It was decided that doing a Hill event during the conference week would not be well attended, so it was decided that we will plan a Hill event for later in the year.

#### Poster Session & Reception

It was discussed about having a reception around the EPG exhibits on Tuesday evening, July 27<sup>th</sup>. All EPG exhibits will be proximally located.

#### Hill Visits

Hill visits will be held on Wednesday, July 28<sup>th</sup> at 12 noon. This will provide a time separate from the meeting for Partner members to visit congressional offices to provide information on the work of the Center. Serena L. and Maura A. are currently planning this activity.

#### National Meeting Symposium

The symposium will focus on how policy is used to translate science into actual practices. Three different ways to affect policy will be discussed: legislative (i.e., Children's Health Act), regulatory (i.e., folic acid), and voluntary (i.e., AAP). Barbara K. is currently planning this activity.

#### Awards

The deadline for nominations for conference awards has passed. George J., Clarke R., and Barbara K. will work on developing criteria for the EPG Award.

#### Exhibits

Barbara K. has sent out exhibit information on how to exhibit and will send out another reminder of the deadline to the Partners Listserv. Everyone is encouraged to exhibit as it will be an opportunity to network.

**\*\*Barbara K. encourages all Partners Group members to get the word out about the NCBDDD conference. For more information about the conference, visit the NCBDDD website at [www.cdc.gov/ncbddd/conference.htm](http://www.cdc.gov/ncbddd/conference.htm).**

### *Committee Updates*

#### Policy & Programs

George J. reported on behalf of Jim R. on the NCBDDD Survey. There were approximately 19 responses. Jim R. will send out another reminder requesting additional responses to the Partners Group and will extend the deadline for another two weeks. After he receives additional feedback, he will then report on the findings.

#### Membership, Finance and Communication

Jane C. was not available to report on the development of the by-laws for the Partners Group.

#### Education and Advocacy

Clarke R. reported that the April 8<sup>th</sup> Hill briefing was highly publicized and that he will continue to publicize events of the Partners Group.

#### External Liaison

Jeremy S. will send out another reminder to the Partners Group to link their organization to the NCBDDD website because some of the Partners are still not represented on the site. To link your organization to the site, send an email to Jeremy S. at [tsdc@tsa-usa.org](mailto:tsdc@tsa-usa.org) or Barbara K. at [bwk1@cdc.gov](mailto:bwk1@cdc.gov).

### *Other Issues*

For those interested in becoming a member of the Partners Group, contact Barbara K. at [bwk1@cdc.gov](mailto:bwk1@cdc.gov). Also, for additional questions, comments or suggestions, contact Jeremy S. at [tsdc@tsa-usa.org](mailto:tsdc@tsa-usa.org). Contact George J. at [gjesien@aucd.org](mailto:gjesien@aucd.org) or Barbara K. on activities of the EPG.

Meeting adjourned at 2:40pm.

**\*The next meeting of the EPG and the Executive Committee has been re-scheduled for Friday, June 11<sup>th</sup> at 1:30pm (EST) – open to all current and potential EPG members.**